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THE NEED FOR THE RE-EDUCATION OF THE TUBERCULOUS
INDIVIDUAL IN TERMS OF HIS HANDICAP

Service Paper

Submitted by

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(B.S. in Industrial Arts Education,
Buffalo State Teachers College, N.Y., 1934)

In partial fulfillment of requirements for
the degree of Master of Education

1947

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May 9, 1947
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CHAPTER I

STATEMENT OF THE PROBLEM

The problem on which this study is based is that of determining the need and scope of a program of medical education of the tuberculous individual while he is in the sanatorium. Specifically, this study seeks through primary and secondary sources to locate and interpret data that might contribute answers in full or in part to the following questions:

1. Is there a need for the medical education of the tuberculous individual?
2. If the need exists, to what extent is it recognized by (a) medical authorities and (b) rehabilitation specialists?
3. What is the attitude of physicians concerning the problem of patient education?
4. What evidence can be presented concerning patients' knowledge of tuberculosis?
5. To what extent have programs of education been developed in sanatoria? How extensive are these programs? What do they include?
6. What principles should underlie the development of

programs of education for tuberculous patients in sanatoria?

7. What, if any, can be recommended as promising practices for implementing these principles?

Significance of the Problem

Relevant facts concerning tuberculosis.-- Each year in the United States alone, 55,000 people die from tuberculosis. Tuberculosis is still the leading cause of death between the ages 15 to 34, according to United States Census Bureau figures. The greatest death toll from tuberculosis is during the most productive years of life. Much has been done, however, to cut down the death toll. In the year 1900, the death rate from tuberculosis was approximately 200 per 100,000 of population. Today, the death rate is approximately 45 per 100,000 of population. Much remains to be done, however. Chadwick and Pope^{1/} point out the following:

Much has been accomplished by organized effort to control tuberculosis since the National Tuberculosis Association came into being in 1904. In the early years of this association the stress was put upon treatment, later on prevention, then on health education, case finding, and research.

The four major objectives of the Tuberculosis Control Division of the United States Public Health Service^{2/} are:

^{1/}Henry D. Chadwick, M.D. and Alton S. Pope, M.D., The Modern Attack on Tuberculosis, Revised edition, The Commonwealth Fund, New York, 1946, p. 3.

^{2/}Herman E. Hilleboe, M.D. and Norvin C. Kiefer, M.D., "Rehabilitation and Aftercare in Tuberculosis," Public Health Reports (March 1, 1946), Vol. 61, No. 9, United States Public Service, Washington, D.C.

(1) Case finding to discover all tuberculosis in an early stage; (2) adequate treatment and isolation facilities for all patients; (3) aftercare and rehabilitation; (4) protection of the patient's family against economic distress.

Some characteristics of tuberculosis and their implication.-- The word tuberculosis as employed in this thesis refers to pulmonary or tuberculosis of the lungs. Tuberculosis is a chronic disease, the treatment of which involves long-term hospitalization. From a clinical point of view, tuberculosis is curable. However, a moderate way of life is necessary in order to insure a permanent cure. From a pathological point of view, tuberculosis can be arrested but not permanently cured. Therefore, the disease is a potential danger to the individual who has it. There are no "hard and fast" rules to follow in order to stay well, because every case of tuberculosis is different from every other case. The best prescription for staying well is an elementary knowledge of the nature of the disease coupled with sound common sense judgment.

Conditions which make tuberculosis control a difficult problem.-- There are no laws compelling patients with active disease to accept treatment and to continue treatment until recovery. The problem of curing and staying cured is fraught with difficulty. It is at the time of diagnosis that the tuberculous individual must make the decision to take the cure for an indefinite period of time. Such a decision

requires self-discipline and moral courage. The attitude of the patient toward his treatment is the keystone of rehabilitation.

Some statements of medical authorities suggesting unsolved problems.-- According to Dr. Aitken,^{1/} who has written a great deal on rehabilitation: "50 per cent of patients discharged from sanatoria still die of tuberculosis within five years." The nature of tuberculosis suggests a number of difficult problems, as Dr. H. A. Pattison^{2/} states in his book on rehabilitation: "The three facts that have made tuberculosis such a stupendous world problem are its communicability, its chronicity, and its tendency to relapse or recur."

The fact that early tuberculosis may not have any recognizable symptoms makes the problem of case finding more difficult and hence the minimal case may develop into a more advanced one before being recognized. Dr. Pope^{3/} of the Massachusetts Department of Public Health recently stated, "In Massachusetts we have been particularly disturbed by the fact that with the present high rate of wages many people

^{1/}A. M. Aitken, M.D., "Work Tolerance Following Tuberculosis," Tuberculosis Abstracts, Vol. XV, No. 8, National Tuberculosis Association, August, 1942.

^{2/}H. A. Pattison, M.D., Rehabilitation of the Tuberculous, Livingston Press, Livingston, New York, 1942, p. 1.

^{3/}Alton S. Pope, M.D., "Why Tuberculosis Is Increasing in Massachusetts," Massachusetts Health Journal (December, 1944), 25: 6.

with tuberculosis continue to work or take new jobs instead of accepting sanatorium care."

A thorough knowledge of the epidemiology of tuberculosis is not an effective defense against the spread of the disease. A great deal is known about tuberculosis, but medical knowledge which seems to be the property of the medical profession does not prevent the patient from breaking down with tuberculosis once he has cured it. Something seems to be wrong when so many patients die within such a short period of time after having been cured of their disease.

Facts of a prophetic nature regarding tuberculosis control.-- Much has been said about the control of tuberculosis in the Veterans' Administration. Louis I. Dublin^{1/} of the Metropolitan Life Insurance Company stated in a recent article the following:

From present indications, there is danger, that the Veterans' Administration may be compelled to function under the same regulations and procedures which govern the care of veterans of World War I. There is already evidence that all is not well with the new tuberculosis victims, and that they are showing the same restlessness, the same abandonment of regular hospital care, which has produced such calamitous results among the older men. The stage may be set for another great medical tragedy; and unless we take action, I believe that lack of discipline and mistaken generosity may not only take their toll of these young men--who should by all reason get well and be sent back to their communities to take up a useful life again--but may also seriously delay our control of tuberculosis in the general population of the country.

1/Louis I. Dublin, "Function of the Health Officer in the Control of Tuberculosis among Veterans," American Journal of Public Health (December, 1943), 33: 1425-1429.

Sanatoria populations can be roughly divided as follows according to Philip P. Jacobs^{1/} in his book on tuberculosis control,

While no exact and reliable figures are available, it may be estimated that approximately 50% of our tuberculosis hospital patients are going to be invalids at home or in institutions for the rest of their lives and are therefore not capable of full rehabilitation. Another 30% can and probably will return to their former work. This includes housewives, for whom social treatment leading to full rehabilitation is most necessary. Included in this group are also a number of employees of progressive industries which make arrangements to re-employ workers who have completed a satisfactory course of medical and social treatment. Children under 16 years of age constitute another group for whom a special regimen of social treatment is necessary. They constitute presumably 5% of the patients. This leaves approximately 15% in need of a full course of social treatment, designed to lead to ultimate rehabilitation. In the United States, this group numbers about 25,000 to 30,000 patients.

But as Dr. Aitken has stated, 50 per cent of those patients discharged from sanatoria die or suffer a reactivation of their disease within five years. Why? If 50 per cent or more patients break down again or die within five years after being discharged^{2/} from the sanatorium; and of this 50 per cent, 30 per cent will return to their former work, it can be assumed that the reason for the breakdown was not necessarily due to unsuitable work, or in other words, the problem is not necessarily a vocational one. It may be an educational

^{1/}Philip P. Jacobs, The Control of Tuberculosis in the United States, National Tuberculosis Association, New York, 1940, pp. 146-147.

^{2/}Discharged patients does not include those who leave against advice, or A.O.R. (at own risk).

problem. As Jacobs ^{1/} states: "The tuberculosis hospital or sanatorium is or should be a school for training patients in a new way of living, which is the only known cure for tuberculosis."

While the patient is in the sanatorium, he has his life regulated for him, and consequently he doesn't have to think for himself. He may get wrong impressions regarding tuberculosis from other patients. Holland Hudson describes the sidewalk authority on tuberculosis as the ward oracle. A recent magazine article by Mr. Hudson ^{2/} suggests the difficulty encountered by patients in sanatoria. He states,

Ever present throughout sanatorium treatment lurks the ward oracle or his female counterpart. He has the valor of ignorance and a loud voice. He knows all the answers; often he means well. Doctor and nurse struggle to correct the misinformation and misinterpretation regarding tuberculosis and its treatment with which he regales every patient within hearing distance.

Mr. Hudson ^{3/} further states, "The only effective defense against the oracle's pseudo-science is the systematic health education of patients." Doctors say in effect to the patient, "Whether you get well or not depends to a large extent upon you." If the cure and aftercare depend to a large extent upon the patient, doesn't it seem logical that all possible care should be exercised to be sure that the patient knows all

^{1/}Op. cit., p. 147.

^{2/}Holland Hudson, "Six Traffic Signals in the Rehabilitation of the Tuberculous," Journal of Rehabilitation (March, 1946), 12: 17-19+.

^{3/}Ibid.

PUBLISHED WEEKLY
535 N. Dearborn Ave., Chicago, Ill. 60610
Subscription price, \$5.00 per year in advance

Vol. 112

Number 11 November 11, 1963

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he is supposed to know about his handicap? If so much of the battle depends upon him, the doctor owes it to the patient to tell him more about the disease. It is not a question of education so much as it is a question of re-education. Under present conditions, can we assume that the average tuberculous patient is capable of shouldering the responsibility which is placed upon him without a more thorough knowledge of tuberculosis and what it means to him?

Conditions suggesting lack of education.-- In the foregoing chapter, Jacobs has pointed out the general make-up of sanatoria populations. Aitken has pointed out that 50 per cent of those patients who are discharged each year from sanatoria, break down or die within five years. It can be assumed that the reason was not necessarily a vocational reason; that is, it was not due to unsuitable work. Is medical science only 50 per cent effective? Can we afford to neglect patient education, when the cost is so great? In the chapters which follow, further evidence will be presented, suggesting a need for medical education of tuberculous patients. The evidence will be presented first from the opinions of medical authorities, and secondly from the results of an experimental study of a group of patients.

CHAPTER II

AUTHORITATIVE OPINION CONCERNING PATIENT EDUCATION

Medical Opinion and Patient Education

The doctors' increasing awareness of the problem of education.-- In examining the literature concerning patient education, one is confronted with fairly general agreement as to need for the education of the patient. There is, however, no general agreement as to content of a program of education or of methods to be used in it. The following expressions of medical opinion reveal the attitudes of doctors concerning patient education.

In stressing the importance of the education of the patient, Dr. Esmond Long ^{1/} states:

It is an accepted fact that in the cure of tuberculosis education of the patient is one of the most important factors, ranking with rest, adequate food, and suitable hygienic environment, the time honored prescriptions for treatment. In no one of the chronic diseases does knowledge of the nature of his ailment protect the patient against unfavorable progress and relapse more than in pulmonary tuberculosis.

Stone and Dufault ^{2/} concur with Long on the necessity of

1/Esmond R. Long, M.D., Introduction to 1000 Questions and Answers on Tuberculosis by Heise, National Tuberculosis Association, New York, 1935.

2/Moses J. Stone, M.D. and Paul Dufault, M.D., The Diagnosis and Treatment of Pulmonary Tuberculosis, Lea & Febiger, Philadelphia, 1946, p. 298.

the patient understanding his handicap. They state: "The tuberculous must learn to adjust himself to his handicap and ordain his life accordingly. His working capacity may be reduced by 10 per cent or by 50 per cent. He must know where he stands."

The physician in tuberculosis must be unusually gifted in the art of counseling. He must understand his patient well enough to know when to be truthful and when to be silent. As Peck and Willis^{1/} point out:

Much time must be spent with a patient in helping him to become adjusted to his changed situation. Psychological, social and economic problems must be discussed with him and simplified. He must be actually indoctrinated with a philosophy which permits him to accept his disease with equanimity and to submit completely and cheerfully to rigid discipline.

An appeal must be made to the patient's intelligence in order to induce him to accept his tuberculous condition as a cornerstone, on which to build an educational program. There is a psychological moment at which to begin the education of the patient, and the moment is at the time of diagnosis, as Riley^{2/} states, "The foundation for successful treatment in tuberculosis is laid when the doctor tells the patient that he has the disease. Psychologically, medically and

^{1/}William M. Peck, M.D. and Henry S. Willis, M.D., "Bed-Rest in Tuberculosis," American Review of Tuberculosis (July, 1945), 52: 18.

^{2/}J. D. Riley, M.D., "The Psychological Moment in the Treatment of Tuberculosis," American Review of Tuberculosis (October-November, 1946), 54: 343.

economically, this may well prove to be the biggest moment in the patient's life." If the individual is fortunate enough to have a family doctor who is familiar with tuberculosis, such a moment may be fruitful. If, however, the family doctor does not interpret the diagnosis of tuberculosis adequately, the individual may be disillusioned when he faces the sanatorium doctor, and he realizes the full implication of his diagnosis. Concerning the role of the sanatorium physician, Riley^{1/} further states,

Once the patient is in the sanatorium, he becomes the responsibility of the sanatorium physician. Immediately upon admission the sanatorium physician should explain to the patient that the treatment of tuberculosis is essentially educational. First, it is necessary for every patient to unlearn false notions about tuberculosis.

Intelligence is the most potent factor that can be directed against disease. No question asked by an earnest patient is too insignificant for an answer. No fact that will aid him in recovering health should be withheld from him.

The education of the patient as to the necessity for continuing his treatment has been stressed by Wolford^{2/} in a recent article concerning tuberculosis among veterans. The education of the patient as an effective defense against his leaving A.O.R (at own risk) is strongly recommended by Banyai

^{1/}Ibid., p. 342.

^{2/}Roy A. Wolford, M.D., "The Tuberculosis Program of the Veterans' Administration," American Review of Tuberculosis (November, 1944), 50: 380.

and Cadden^{1/} in an article concerning compulsory hospitalization. They state:

A great deal of effort and time have been spent in counteracting the tendency of patients to leave tuberculosis institutions against medical advice. Recommendations and practices with any hope of promise have been made part of the daily procedure in sanatoria facing this problem. Special emphasis has been laid on adequate mental conditioning of the patient with particular reference to the discussion of his disease at the time of his admission and on subsequent occasions relative to his progress.

Further evidence as to the increasing awareness of the medical profession to the problem of patient education has been exhibited at a recent conference on rehabilitation which was held in Washington. The conference was sponsored by the Office of Vocational Rehabilitation with the Tuberculosis Control Division of the United States Public Health Service and the National Tuberculosis Association. The purpose of the conference was to determine the specific duties of the Institution and the Public Health Nurse, the Medical Social Worker, Occupation Therapist, Educational Advisor, Vocational Advisor, and the Physician relative to a program of rehabilitation.

The following excerpts from the conference report reveal the opinions of medical specialists concerning the education of the patient:

1/Andrew L. Banyai, M.D. and Anthony V. Cadden, M.D., "Compulsory Hospitalization of Open Cases of Tuberculosis," American Review of Tuberculosis (August, 1944), 50: 136.

Bobrowitz^{1/} states:

I believe that health education of the patient is the doctor's prerogative. In our routine, right after admission we give the patient illustrated lectures on the important phases of tuberculosis, including rehabilitation. I don't mean that the nurse is not an important individual in the education of the patient. In the daily practices in the wards, in teaching health habits, in answering questions, and so forth, she is important. But I think that first the doctor must get across certain things which only the doctor can do.

Another point of view is expressed by Lincoln^{2/} who states the following:

The only thing that I have found worth while is the close supervision of the doctors in immediate charge of the wards, making patient education an individual job. In a ward we may have as patients a doctor, a lawyer, and a laborer who can hardly speak English. No one program can fit it all. It seems to me that the doctor is the man to explain the technical aspects and the nurse is the person who can keep up the morale and encourage patients.

Thompson^{3/} concurs with Lincoln in that he believes that patient education is an individual job. He states: "I tell the doctors that when they are making rounds in the wards, if someone asks a question which calls for a job of health education, they should stand out in the middle of the floor and answer so everyone can hear."

1/Isadore D. Bobrowitz, M.D., Medical Supt., Municipal Sanatorium of City of New York, Otisville, N. Y., Rehabilitation of the Tuberculous, Proceedings of Conference, Washington, D.C., March, 1946, National Tuberculosis Association, p. 12.

2/N. Stanley Lincoln, M.D., Director, Herman M. Biggs Memorial Hospital, Ithaca, N. Y., ibid., p. 13.

3/Rollin Thompson, M.D., Supt. and Medical Director, State Tuberculosis Sanatorium, Orlando, Fla., ibid., p. 14.

Directly or indirectly, the above quotations from medical authorities point out the need for the education of the tuberculous patient. While the literature reveals increasing agreement among authorities concerning this need, the quotations included above suggest the further problem of determining the content and method of an educational program to meet the need.

Increasing awareness of the role of the patient.-- Tuberculosis is a public health problem with sociological and economic implications. Its control lies to a large extent in the hands of those who have had it. If all the people who have taken the cure, can with proper care remain cured, the control of tuberculosis need not be such a great problem. Treatment becomes a mockery if the product (the cured patient) of such expensive treatment does not know how to take care of himself in order that he may remain permanently cured. The patient entering the sanatorium for the first time is forced to make a difficult and very necessary adjustment. The adjustment from an active to a totally inactive life is the more difficult if the individual does not feel very sick. The tuberculous individual may not experience any of the characteristic symptoms in the early stages of his infection. As Chadwick and Pope^{1/} point out in their book, "The X ray

^{1/}Henry D. Chadwick, M.D. and Alton S. Pope, M.D., The Modern Attack on Tuberculosis, Revised edition, The Commonwealth Fund, New York, 1946, p. 40.

will demonstrate an infiltration in the lungs before characteristic symptoms appear and thus long before signs of the disease can be detected." If the tuberculous individual is really tired and run down, the thought of spending 24 hours a day in bed does not strike him too hard. However, he may come to the sanatorium full of hope for a quick recovery, and consequently may be disillusioned. For example, if he is placed in a ward with a patient who has by chance spent several years in the process of taking the cure, the results may be unfortunate. A typical conversation between two patients might run as follows:

New patient: "My doctor told me that I was to come here for six months for observation."

Old patient: "That's what they told me three years ago."

Such situations are by no means rare. Patients have been known to leave the sanatorium the same day they came in because of such discouraging situations. It is true that the individual must have the fortitude to go through with the problem at hand, but first impressions go a long way with an individual entering the sanatorium for the first time. Every effort must be exerted to aid the patient in making his initial adjustment to sanatorium life. Concerning sanatorium life, Chadwick and Pope^{1/} point out the following:

Experience is the best teacher, and living a sanatorium life is a personal experience that makes the patient aware of his handicap and of the

1/Ibid., p. 56.

necessity of keeping within the limits of the safety zone defined by his disease. Rest, both mental and physical, is the keystone upon which recovery is built. This is the first lesson that a patient has to learn.

While in the sanatorium, the patient keeps within the safety limits, because his routine is regulated for him.

The medical education of the patient and the rehabilitation of the patient are so closely related that they will be dealt with in the same chapter. Their close relationship is summed up by Heise^{1/} as follows:

The education of the patient is one of the principal accomplishments of sanatorium residence. The knowledge of the uncertainties of the disease, the reasons why living, working and environmental adjustments must be made, as well as how much recovery and its maintenance depend upon the patient himself, all furnish the background for his care after leaving the sanatorium. For a considerable period of time after discharge, his disease is a serious potential danger.

In the following section on rehabilitation other evidences of the need for the education of the tuberculous patient are suggested by rehabilitation authorities whose work makes it possible for them to present another viewpoint concerning the problem of the tuberculous patient.

Meaning of Rehabilitation

Relation of medical education to rehabilitation.-- Rehabilitation as defined by the National Council^{2/} is, "The

^{1/}Fred H. Heise, M.D., "The Importance of Postsanatorium Care of the Tuberculous," American Review of Tuberculosis (October-November, 1946), 54: 344.

^{2/}National Council on Rehabilitation, 1790 Broadway, N.Y., 1945.

Restoration of the handicapped to the fullest physical, mental, social, vocational and economic usefulness of which they are capable." Such a definition would cover all types of physical handicaps. In order to rehabilitate the handicapped person, it is necessary to understand as much as possible about the nature of the affliction. The nature of the handicap predisposes the plan of rehabilitation to be followed. Rehabilitation of the tuberculous is closely allied to medicine or treatment and presupposes health education of the patient. In other words, it is assumed that the patient has learned enough health education by virtue of the sanatorium experience. However, it would seem that such health education was lacking when so many patients break down after discharge from the sanatorium. Holland Hudson^{1/} points out, "Over and over, clinicians have assured us that their most lamentable readmissions are patients whose occupation has been suitable but whose play-life has been recklessly exhausting."

Nature of rehabilitation of the tuberculous.-- Rehabilitation in tuberculosis differs from other types of rehabilitation because of the fact that tuberculosis differs from other types of physical handicaps. Reuling^{2/} states,

1/Hudson and Fish, Occupational Therapy in the Treatment of the Tuberculous Patient, National Tuberculosis Association, New York, 1944, p. 108.

2/James R. Reuling, M.D., Rehabilitation of the Tuberculous, Bulletin of the National Tuberculosis Association, February, 1946, p. 19.

Once ill with any disease most persons want to be well again and often are entirely so, for many other diseases are not recurrent in character. Not so with tuberculosis. Although most patients have not had enough health education to understand this fully, many do know that tuberculosis once found does not leave them free as they were before. They fear recurrences.

The whole rehabilitation process beginning with diagnosis is inescapably tied up with treatment. It is constantly fraught with danger. Hudson^{1/} calls the danger--forks in the road to recovery. He states them as follows,

The first fork in the road to recovery occurs at the time of diagnosis, except when treatment is undertaken too late for possible recovery.

Patients have been encouraged to read, to use their minds and their hands in some constructive way. Such services range all the way from the development of new avocational resources to prevocational study.

The next fork in the road is encountered when the patient is promoted from a horizontal passive life to a vertical, active role, when he gains an ambulant status.

The next fork in the road occurs in the counseling process. Some intervals in every patient's experience are none too pleasant to remember. Sometimes a patient attempts to turn his back upon the entire experience, to have done once and for all with doctors and nurses and all the apparatus of diagnosis and treatment.

The final turn for the counselor and for vocational rehabilitation is a long-range follow-up on the employed client.

In summing up rehabilitation of the tuberculous, the

^{1/}Holland Hudson, "Six Traffic Signals in the Rehabilitation of the Tuberculous," Journal of Rehabilitation (March, 1946), 12: 17-19+.

main points would seem to be as follows: (1) At the time of diagnosis, the patient must accept sanatorium treatment immediately; (2) He should make the most of hospital rehabilitation services (library, occupational therapy, prevocational activity and vocational guidance); (3) He must play fair with the doctors and report for medical check-up as prescribed after discharge.

Attitude of doctors as to the relative place of rehabilitation in the total picture.-- Rehabilitation is relatively new in tuberculosis work, and it presents a definite challenge. According to a report of the Committee on Rehabilitation of the American Trudeau Society,^{1/} much remains to be done. The report states,

Even though we have known the unmet needs of our disabled tuberculous patients and have charted for many years workable plans for their rehabilitation, these needs have remained unmet. The chief reasons for this failure may be given as follows,

1. With the exception of the physical restoration of the patient the physician has shown a lack of interest in a planned program of rehabilitation.

2. This may in part have been due to the fact that governing boards and health departments could not find sufficient funds for their budgets for purposes other than case-finding and treatment of the physical condition.

3. This attitude may also have been due to the fact that, in many small and some large institutions where there is a lack of beds for the tuberculous, the turnover of patients is too rapid

^{1/}American Trudeau Society, "Report of the Committee on Rehabilitation," American Review of Tuberculosis (August, 1945), 52: 176-177.

to make an in-sanatorium rehabilitation program workable.

Such causes for failure and the inequities in the general program of rehabilitation will undoubtedly continue. With the passage, however, of the Barden-LaFollette Act of 1943 by Congress, we have for the first time a firm foundation on which a constructive program of rehabilitation may be built.

The relative importance of rehabilitation is summed up by Hilleboe^{1/} as follows,

Rehabilitation and after-care are absolute essentials for the tuberculous, as well as for all physically handicapped persons. Rehabilitation commonly is thought of as the process of restoration of economic self-sufficiency to a disabled person. There are, however, a few diseases in which rehabilitation is a more complex problem. Tuberculosis is an outstanding example, because it is resistant to complete cure and always likely to recur. In this disease rehabilitation must serve the added purposes of protecting the patient against recurrence and the public health against spread of the disease.

Aftercare and Its Implications

Work tolerance and its relation to aftercare.-- Aftercare implies the period immediately following discharge from the sanatorium. It is probably the most critical phase in the rehabilitation process. It is the period when the patient is most likely to overdo. Sanatorium cure hours must gradually be broken, and it becomes a tempering process, different for each individual. Doctors state that the most

1/Herman E. Hilleboe, M.D. and Norvin C. Kiefer, M.D., Rehabilitation and Aftercare in Tuberculosis, Public Health Reports, Vol. 61, No. 9 (March, 1946), Tuberculosis Control Issue No. 1, United States Public Health Service.

critical period for the patient is the first two to three years following discharge from the sanatorium. During the period of aftercare the patient is told that he should report for periodic X ray and physical examination every two to three months for the first year. What does the patient do in the meantime? Nobody knows and nobody cares, because it is assumed that the patient knows how to take care of himself. To insure proper physical hardening on a graduated basis, Dr. Aitken^{1/} suggests the following,

In order to establish with more surety that the patient can withstand sustained efforts, a period of physical rehabilitation should be followed before discharge of the patient. Before it can be certain that the patient can lead a normal life and stand up to ordinary work conditions, sanatorium routine and cure hours should be broken. One of the hardest things for the patient is to discontinue the mid-day rest period. If he can put on a full work schedule for forty hours a week for a few months before discharge and is able to play after work without undue fatigue, he should be able to do the same outside. This can be readily done in a sanatorium, where there is a constant need for help and often to the advantage of the sanatorium.

It is true that sanatoria today do not keep patients long enough to establish an eight-hour work tolerance. The usual procedure is to prescribe so many minutes of exercise, usually walking, but no planned work activity, because most sanatoria do not have enough Occupational Therapy and

^{1/}A. M. Aitken, M.D., Work Tolerance Following Tuberculosis (Paper given at annual meeting of National Tuberculosis Association, May, 1942), Tuberculosis Abstracts, Vol. XV, No. 8 (August, 1942).

Pre-vocational services for the patient to engage in, in order to build up work tolerance. The reason for the lack can be explained in the report of the American Trudeau Society's Committee on Rehabilitation.^{1/} Existing conditions make it difficult for the medical director to keep a patient in the sanatorium until he has been conditioned to a 35 to 40 hour per week work tolerance. As a result he is discharged from the sanatorium with a maximum work tolerance of 2 to 4 hours. The way the tuberculous patient increases his physical activity from 4 to 8 hours or more is usually a haphazard affair with no medical supervision, save his periodic check-up in the out-patient department.

Sanatorium Responsibility

The place of rehabilitation in the sanatorium.-- The rehabilitation process begins as soon as the patient is willing to accept treatment. Doctors have pointed out the necessity for taking rest treatment and continuing such treatment along with auxiliary medical therapy, until recovery, even though it might take from two to six years or more. Voluntary isolation is a public health necessity, and society's responsibility. The sanatorium should provide a library service, occupational therapy and pre-vocational services, educational and vocational counseling, and social service. The effectiveness of rehabilitation service depends upon

1/Op. cit.

the relative importance given to it by the medical staff.

^{1/}
Hilleboe states,

Rehabilitation is a from of treatment. Obviously during the period of diagnosis and early hospitalization, medical care is paramount; but at some point during the period of hospitalization, vocational guidance and training constitute a large portion of treatment and are continued into the immediate post-sanatorium period. As the patient improves clinically, rehabilitation is intensified until he is ready for discharge, at which time part-time work is permitted. Later the patient gradually acquires a mastery of some skill and finally secures a full-time job.

The increasing scope of sanatorium treatment.-- As ^{2/}
Jacobs has stated, the sanatorium should be a training school for patients. One needs only to view some of the consequences of inadequate rehabilitation service, to grasp ^{3/}
the importance of them. Berman and Berman state,

Those who are interested in helping a patient to use the medical care necessary for recovery and to accept a possible physical limitation, find challenging problems in work with the tuberculous. The importance of this may be realized when hospitals in different parts of the country report that from 22 to 65 per cent of their patients leave "At Own Risk (A.O.R.)!"

There are many reasons why patients leave the sanatorium before their disease is arrested; it may be a family difficulty, boredom, or a lack of proper knowledge concerning the seriousness of the disease. Whatever the reason, the sanatorium

1/Op. cit.

2/Op. cit.

3/Jean Berman and Leo H. Berman, "The Signing Out of Tuberculous Patients," The Family (April, 1944), 25: 67-73.

has a challenge to meet.

Concerning the responsibility of the sanatorium, Heise^{1/} has the following to say in relation to the scope of treatment,

The sanatorium, to complete its course of treatment, should conduct its physically able patients through all the stages of rehabilitation until a maximum work tolerance of eight hours has been reached. Then the patient is fully rehabilitated. Others should be brought to their maximum work tolerance and be put on part-time work or given work in a sheltered workshop. Not all sanatoria have such a complete program and patients, with or without medical approval, are discharged to return to their homes and families.

Discharge and Follow-Up

The need for constant vigilance.-- Graduation from the sanatorium could also be called commencement because it is the beginning of a new life of moderation and caution. As Chadwick and Pope^{2/} point out in their book, "Patients discharged from sanatoria should be considered as having completed only the first phase of treatment and should return at frequent intervals for consultation during subsequent years." The patient's knowledge and understanding should supplant fear. As Pattison^{3/} states, "The danger and the fear of a return of activity of the disease processes hang like a

^{1/}Fred H. Heise, "The Importance of Postsanatorium Care of the Tuberculous," American Review of Tuberculosis (October-November, 1946), 54: 344.

^{2/}Op. cit., p. 60.

^{3/}Op. cit., p. 52.

sword of Damocles over the victim of tuberculosis for years."

Fear and insecurity are ever present with tuberculous patients. The best way to combat fear is a knowledge of the cause of the fear. As DeSchweinitz^{1/} points out in his classic book on social work, "The surest way of overcoming trouble is to face it, squarely and without evasion, is to appreciate what it involves, to recognize it as it is." A mortal fear of the disease is apt to cause one of two reactions on the part of the patient: (1) He experiences a constant feeling of insecurity, or (2) he casts all fear aside and takes a fatalistic view of his future. Either viewpoint may prove disastrous.

Need to See the Problem as a Whole

The need to follow through on the job.-- Getting the patient well is only a partial solution to the problem of tuberculosis. Rehabilitation is just as necessary as treatment. Hilleboe^{2/} sums up the problem as follows,

There is a tendency to regard rehabilitation and aftercare and protection against economic distress as auxiliary services instead of fundamental needs. They are thought of as gifts discriminately bestowed rather than as a capital investment in the present to avoid perpetual and larger expenditures in the future.

The patient as the key to the situation.-- There appears

1/Karl DeSchweinitz, The Art of Helping People Out of Trouble, Houghton Mifflin Company, New York, 1924, p. 90.

2/Op. cit.

to be an increasing awareness as to the importance of the tuberculous patient in the whole problem of tuberculosis and its control. Max Pinner^{1/} describes the problem as follows,

Every new patient and his family must be taught anew about the dangers of tuberculosis, about its prevention, its treatment and its curability. Every tuberculosis hospital, every group of patients, every new phase in the campaign against tuberculosis creates new problems, new questions, new responsibilities in education and information. And without such education, which must extend to lay public, patients, nurses, social workers, the fight against tuberculosis cannot be won.

Patients taking the cure over long periods, do not want to know only about tuberculosis as such, they want to know quite specifically about their own tuberculosis, about their own outlook, their symptoms, their treatment. They are puzzled by the observation that John must stay in bed, that Sam is on exercise, that Jim gets pneumothorax, and that Jean must have a thoracoplasty. And all the tall tales with which many a newcomer to a tuberculosis institution is welcomed only confuse his already troubled mind.

One might assume from the opinions of leading medical authorities on tuberculosis, that there are several adjuncts to actual medical treatment, and that treatment must be broad in nature, so as to include first of all, medical education of the tuberculous patient.

It could hardly be expected that physicians would agree on content and method because the problem is so individualized in nature. It will take considerably more research to determine the content of a medical education program for

^{1/}Max Pinner, M.D., Foreword to Facts that Tuberculous Patients Should Know, New York Tuberculosis and Health Association, New York, 1943.

patients and the various techniques to be used.

The education of the patient is the beginning of his rehabilitation. Rehabilitation is often thought of as merely vocational or job placement. The tuberculous individual must understand his limitations not merely as they relate to his job, but also to his leisure and every other factor in his life.

In the following chapter, more objective evidence will be presented pointing to the need for the education of the patient.

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CHAPTER III
OBJECTIVE EVIDENCE CONCERNING PATIENTS' KNOWLEDGE
OF TUBERCULOSIS

Measurement of Patients' Information
about Tuberculosis

The need for measurement.-- It would appear from the foregoing chapter that patient education is receiving wider recognition among doctors in tuberculosis work. There also appears to be no reason why some form of objective measurement could not be used to ascertain what the level of knowledge of tuberculosis is, among patients at the present time. If it is generally agreed that the tuberculous patient needs to be well informed about his disease, just where should we begin our effort toward education? The answer may be found from some form of measurement. The use of objective measurement in education dates back to the latter part of the nineteenth century. Measurement in education as defined by Wright^{1/} is, "An evaluation of the response of individual or groups to stimuli." More specifically, he defines a test as, "A measuring instrument designed for the evaluation of

^{1/}Wendell W. Wright, Ph.D., Educational Tests and Measurements, Longmans, Green and Company, New York, 1937, p. 4.

II. THE STATE

1. The State of Tennessee is a sovereign and independent nation.

2. The State of Tennessee is a republic.

3. The State of Tennessee is a democracy.

4. The State of Tennessee is a free state.

5. The State of Tennessee is a state of the Union.

6. The State of Tennessee is a state of the Confederacy.

7. The State of Tennessee is a state of the Empire.

8. The State of Tennessee is a state of the World.

9. The State of Tennessee is a state of the Future.

10. The State of Tennessee is a state of the Past.

11. The State of Tennessee is a state of the Present.

12. The State of Tennessee is a state of the Mind.

13. The State of Tennessee is a state of the Heart.

14. The State of Tennessee is a state of the Soul.

15. The State of Tennessee is a state of the Spirit.

16. The State of Tennessee is a state of the Body.

17. The State of Tennessee is a state of the Blood.

18. The State of Tennessee is a state of the Bones.

19. The State of Tennessee is a state of the Marrow.

20. The State of Tennessee is a state of the Nerve.

21. The State of Tennessee is a state of the Sinew.

22. The State of Tennessee is a state of the Muscle.

23. The State of Tennessee is a state of the Tendon.

24. The State of Tennessee is a state of the Ligament.

25. The State of Tennessee is a state of the Joint.

any knowledge, quality or ability."

Present status of measurement on education of the tuberculous patient.-- Standardized tests and questionnaires are widely employed as tools in education. However, they have not been used to any great extent along the lines of tuberculosis. Newman^{1/} states that,

The adaptation of methods so successfully developed in the general scholastic field to patient education has not been wide-spread. In the past, several questionnaires have been developed and used exclusively for survey purposes with various segments of the general population. These questionnaires were drawn up to discover the extent of information about tuberculosis along certain preconceived lines.

Newman, however, has developed a test to be used specifically in a clinical situation. He has spent considerable time in developing a series of questions which represent a cross-section of information about tuberculosis which medical authorities consider essential for the tuberculous patient to understand. A detailed description of the test follows.

Description of the Instrument^{2/}

General information.-- The name of the test is, "What Do You Know About Tuberculosis?" by Joseph Newman.^{3/} The test is designed for use by any literate adult tuberculous patient.

1/Joseph Newman, "Patients' Information about Tuberculosis," American Review of Tuberculosis (July, 1946), 54: 13-14.

2/Copy of the test appears in the Appendix.

3/Published by the National Tuberculosis Association, Copyright 1945. Cost: \$2.26 per 100; manual 10¢; scoring key 2¢; distribution sheet 2¢.

Purpose of the instrument.-- Tuberculosis is an infectious disease. It is spread through existing cases, and can be controlled at the source--the infected individual. The cured individual must remain cured. How can this best be done? More education of the tuberculous patient is one answer. What does the patient already know about his disease? It is the purpose of the questionnaire to ascertain what the patient already knows about tuberculosis. If we can find out what the patient knows now, we will know in which direction to concentrate our educational efforts. In other words, the test is diagnostic in nature.

How the test was constructed.-- The test was made up by literally going through hundreds of leaflets, pamphlets, books, periodicals, and patients' publications in order to select those facts on tuberculosis that have general acceptance as being essential in patients' knowledge. The present questionnaire was derived from a list of 100 original questions.

Administration of test.-- No specific instructions are necessary except a few words as to the purpose of the questionnaire and that there are no passing marks, etc. or, in other words, a paraphrasing of the first three paragraphs on the instruction sheet. There are two sample questions.

Construction of test and information for scoring.-- The questionnaire is composed of 50 items. There are 40 items on which the score is based. There are in addition,

six easy, or O items, that is, items correctly answered by over 90 per cent of the patients, which are not used for scoring, and 4 ambiguous or X items, that were included because it was believed they tapped areas about which the tuberculosis worker might want information (O items are 1, 2, 3, 16, 32, 42; X items are 21, 36, 39, 45). The test can be scored with a stencil in one minute. The test measures the degree of present information about tuberculosis. Intelligence plays a prominent role but not a conclusive role.

Validity and reliability.-- The validity was determined by calculating and comparing the percentages of the patient and expert ^{1/} groups answering each item in a given way. The items which were answered correctly on 90 per cent or over of the patient group were eliminated as being too easy. Correctness of an item was determined by the answers of the expert group. Where at least 90 per cent of the expert group answered an item in a given way, that was taken as the correct answer. If the percentage of the expert group answering in any given way was lower than 90 per cent on an item, that item was eliminated as ambiguous. After the obviously easy and ambiguous items were eliminated, the remaining items were treated for statistically significant differences between the percentage of the patient group answering an item

1/Expert group composed of physicians, nurses, occupational therapists, rehabilitation workers, and research workers.

correctly. This was determined by formula.

Items which had critical ratios of 2 or more were selected. Finally, a group of 40 items remained. The score is based upon a possible score of 40. The reliability of scores based upon the final group of 40 items was calculated by means of the odd-even method, and a Pearson r of .79 as corrected by the Spearman-Brown Formula, with a P.E. of plus or minus .018 was obtained. This coefficient of reliability indicates that the questionnaire has satisfactory reliability, especially in view of the purpose for which it was designed.

Norms.-- The most valuable norms are those created for each institution separately since there is a considerable variation in the background and make-up of institutional populations.

Practical considerations and criticism of the instrument.-- The test is ideal as a diagnostic tool pursuant to a program of medical education for patients. The test is economical to use, it is easy to administer, and it is simple to score. The chief administrative limitation is its obvious great dependence upon language comprehension. It is usable with most native born and with those of foreign birth with adequate language ability.

Significance for rehabilitation.-- The questionnaire was designed as an aid to a program for educating patients as to tuberculosis by determining the level and details of

knowledge before such education is instituted. The score serves not as an absolute measure, but rather as an indicator which will help select those patients who need concentrated attention. Item analysis will indicate areas of weakness. Questionnaire will also serve to stimulate the patients in their desire to acquire correct information and will guide their efforts to obtain such information.

The questionnaire can also be an aid in interviewing and counseling. The range of subjects is wide enough to permit exploration of almost any factor in the treatment and aftercare of the tuberculous. To permit exploration of certain attitudes, the X items have been included.

Findings of the Author

Preliminary use of the questionnaire.-- The original questionnaire was tried out experimentally on patients in the Municipal Sanatorium, Otisville, New York. The Municipal Sanatorium was felt to be an ideal place to try the questionnaire in view of the fact that this institution has an educational program for improving the patients' understanding in tuberculosis. The educational program consists of group lectures for new admissions beginning the day after arrival. Over a period of several months, 84 new admissions were given the questionnaire before they started in the series of lectures. The questionnaire was also given to a group of 111 patients who had been in the institution for some time and

had already gone through the lectures and other educational devices of the institution. Thus the total patient group on which the questionnaire was tried numbered 195 subjects.

Role of intelligence in answering the questionnaire.--

Intelligence plays a prominent role in answering the questionnaire. That it does not play a conclusive role will be seen by the fact that 178 college students (who may safely be considered as of superior intelligence) had a mean score of 30, whereas the mean score for patients who had gone through the educational program was 32. The patients' slightly higher average score apparently would indicate that intelligence is not the all-determining factor. It may very well be that the college students' superior informational background and poise as to taking examinations were the most significant reasons for the close approximation of their mean score to the patients' mean score. This conclusion is substantiated by the fact that 75 per cent of the patient population at the Municipal Sanatorium have a school achievement below the twelfth grade; 38 per cent fall below the eighth grade.

Conclusions of the Author

General summary of questionnaire findings.-- In a recent medical journal, the author^{1/} has summarized his findings as follows:

1/Newman, op. cit., pp. 22-23.

The results of the questionnaire findings show that the following points about tuberculosis are generally understood in the various groups sampled (exclusive of the professional tuberculosis workers):

1. Contagiousness is a factor to be considered in tuberculosis.
2. Tuberculosis is not inherited.
3. Tuberculosis is not fatal.
4. Rest is an important part of treatment.
5. Mental factors are significant in treatment. (A trend towards pessimism and fatalism was found among the patient groups.)
6. Each case of tuberculosis is different.
7. Coughing has no diagnostic value.
8. It is important to have knowledge about tuberculosis as a disease.
9. The best source of information about one's condition is the doctor.
10. Recognition of the value of sanatorium care.
11. The advisability of waiting for a proper medical discharge before leaving the sanatorium.
12. The necessity for follow-up care after discharge.
13. The advisability of sufficient sleep each night.
14. The necessity for hygienic measures in the home.

The author^{1/} continues his summary in regard to other points:

1/Ibid., p. 23.

The following points showed improvement in understanding, comparing the old patients with the new patients:

1. The specific means of acquiring tuberculosis.
2. The viability of tuberculosis germs.
3. Being overweight is of no value.
4. Outdoor work is not advisable.
5. Unlimited exposure to the sun is not advisable.
6. Frequent and numerous visitors are not advisable.
7. The value of making plans for the future while a patient.
8. The inadvisability of judging one's progress by subjective feelings of good health.

The following points were understood to a lesser degree, the degree of misunderstanding ranging from one-fifth to one-third of the groups:

1. Nature of contact for contracting tuberculosis.
2. Isolation at home is not enough as a preventive measure.
3. Tuberculosis may occur at any age.
4. Rest is the most important part of treatment.
5. Inadvisability of delay in treatment.
6. Rest at home without medical attention is insufficient.
7. X ray is the best diagnostic means.
8. The value of climatic factors in treatment.

The following points seemed to be generally misunderstood:

1. Tuberculosis as an illness may run an

the first thing I noticed when I stepped out of the car was the smell of the sea. It was a fresh, salty breeze that seemed to wash away all the worries of the world.

I had heard that the weather was perfect, but I didn't realize how much I needed it. The sun was shining brightly, and the waves were crashing against the shore. It was a beautiful sight, and I felt like I had found a new world.

I walked along the beach, feeling the sand under my feet. The water was so clear, and the sky was so blue. It was a perfect day, and I felt like I was on top of the world.

I had heard that the beach was beautiful, but I didn't realize how much I needed it. The sun was shining brightly, and the waves were crashing against the shore.

I had heard that the beach was beautiful, but I didn't realize how much I needed it. The sun was shining brightly, and the waves were crashing against the shore.

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erratic course.

2. The necessity for radical measures to destroy used paper tissues, such as by burning.
3. Recognition of subtle symptoms of tuberculosis.
4. Association of dramatic and traditional symptoms with all tuberculosis.
5. The significance of negative sputum in relation to progress.

Conclusions of the author concerning specific value of test.-- Individual knowledge of the disease varies as much as each case of tuberculosis. Therefore the chief value of the test is in correcting such variation. There is no broad general understanding or misunderstanding in the various groups sampled by the author. Rather, there is considerable variation in understanding and misunderstanding, concerning tuberculosis.

Application of the Questionnaire Locally

The need for measuring the patients' present knowledge of tuberculosis.-- In assuming that there is a need for the education of the tuberculous patient in terms of the limitations of his disease, one is faced with the question of how much the patient already knows about his disease. We may assume that he already knows something. How much does he know about tuberculosis? Does he have any misinformation? In order to go beyond the statements of authorities concerning the need of patients' education, and to provide more

specific evidence of the need of patient education locally, the Newman Questionnaire was used in two sanatoria open to the writer. In contrast to the Otisville situation, however, no educational program exists in either of the local institutions. Since one principle of education is to begin at the level of the learner, the questionnaire has been tried out with 115 tuberculous patients, in order to find out where the patients' present knowledge begins and leaves off. A description of the local study follows.

Test Findings Obtained Locally

Selection of test group.-- The test group was selected from among the patients at a 170 bed county tuberculosis hospital and a 30 bed municipal tuberculosis hospital. Neither hospital at the time was running at capacity because of the acute nursing situation. The total test group comprised 115 tuberculous patients, 104 from the county institution and 11 from the municipal institution. There were 60 female patients and 55 male patients.

General description of test group.-- The group of tuberculous patients were all English-speaking whites ranging from 18 to 69 years in age. The age distribution is shown as follows in Table 1.

The chief value of a table indicating the age distribution is to show that the ages of most of those tested would not preclude any type of education. The fact that 46.1

The purpose of the study of the relationship between the two variables is to determine whether there is a significant difference in the mean values of the two variables. The null hypothesis is that there is no significant difference in the mean values of the two variables. The alternative hypothesis is that there is a significant difference in the mean values of the two variables. The test statistic is calculated as follows:

$$t = \frac{\bar{x}_1 - \bar{x}_2}{\sqrt{\frac{s_p^2}{n_1} + \frac{s_p^2}{n_2}}}$$

where \bar{x}_1 and \bar{x}_2 are the sample means, s_p^2 is the pooled variance, and n_1 and n_2 are the sample sizes.

The test statistic is compared to the critical value from the t-distribution table. If the test statistic is greater than the critical value, the null hypothesis is rejected. If the test statistic is less than the critical value, the null hypothesis is not rejected. The p-value is also calculated. If the p-value is less than the significance level, the null hypothesis is rejected. If the p-value is greater than the significance level, the null hypothesis is not rejected. The results of the test are summarized in the following table:

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The results of the test are summarized in the following table:

Table 1. Age Distribution in Test Group

Age	Number	Per Cent of Total Group
Under 21.....	12	10.4
21 to 35.....	53	46.1
36 to 50.....	34	29.5
Over 50.....	16	13.9

per cent of the group were between 21 and 35 years of age would seem to indicate that they were not too old to profit from any program of education. In terms of formal education, the test group ranged from the sixth grade to four years of

Table 2. Extent of Formal Education of Test Group

Grade Completed		Number	Per Cent	Cumulative Totals	Per Cent
Elem.	6	3	2.6	3	2.6
	7	2	1.7	5	4.3
	8	17	14.7	22	19.1
High School	9	13	11.3	35	30.4
	10	11	9.6	46	40.0
	11	6	5.2	52	45.2
	12	33	28.7	85	73.9
College	1	11	9.6	96	83.5
	2	10	8.7	106	92.2
	3	4	3.5	110	95.6
	4	5	4.3	115	99.9

college. The distribution in terms of formal education is shown in Table 2.

Preliminary description of test data.-- Since neither institution of which the test group is comprised has a program of medical education for patients, a comparison of scores with those of Otisville would not be relevant. However, the value of the test lies in an item analysis of the results. By making an analysis of the test results, the reader can get a better picture of the items about which for the groups tested there is correct information concerning tuberculosis and also where there is a lack of proper understanding concerning tuberculosis.

Use of test in two Massachusetts sanatoria.-- Table 3, which shows the test results, is explained as follows: In the first column there is listed the item most frequently answered incorrectly down to the one least frequently answered incorrectly. The reason that there are only 30 instead of 40 in the total rank order is because some of the items were answered incorrectly by the same number of patients in each case; for example, item number 30 and 7 both ranked 13th in the order of incorrect responses. Items 4, 38, and 43 all ranked 17th in the order of incorrect responses, etc. The most frequent incorrect response was on item number 18. The least frequent incorrect response was on item number 23. The second column contains the item numbers as they appear in

Table 3. Responses of 115 Patients to 40 Items of Newman's Questionnaire

Rank Order	Item Number	Number of Incorrect Responses	Number of Unanswered Responses	Total Number of Incorrect and Unanswered Responses	Percentage of Total Group
(1)	(2)	(3)		(4)	(5)
1	18	87	8	95	82.6
2	34	90	2	92	80.0
3	50	63	3	66	57.3
4	6	53	6	59	51.3
5	47	53	2	55	47.8
6	25	41	5	46	40.0
7	27	39	4	43	37.3
8	13	39	3	42	36.5
9	31	28	6	34	29.5
10	24	28	2	30	26.1
11	11	25	4	29	25.2
12	26	23	5	28	24.3
13	30	22	3	25	21.7
	7	24	1	25	21.7
14	8	17	5	22	19.1
15	49	14	7	21	18.2
16	22	17	2	19	16.5
17	4	13	5	18	15.6
	38	17	1	18	15.6
	43	14	4	18	15.6
18	5	15	2	17	14.7
	17	14	3	17	14.7
	20	15	2	17	14.7
19	33	11	3	14	12.1
20	19	11	2	13	11.3
	37	11	2	13	11.3
	44	10	3	13	11.3
21	35	6	6	12	10.4
	10	10	2	12	10.4
22	40	8	2	10	8.6
23	9	8	1	9	7.8
24	28	8	0	8	6.9
	41	6	2	8	6.9
25	29	4	3	7	6.1
26	14	5	1	6	5.2
	48	5	1	6	5.2
27	12	4	1	5	4.3
28	15	2	2	4	3.4
29	46	2	1	3	2.6
30	23	2	0	2	1.7

the Newman Questionnaire. The third column contains the number of incorrect and unanswered items. Unanswered items are considered incorrect insofar as scoring is concerned. The fourth column contains the total number of incorrect responses on each item of the questionnaire. The last column contains the percentage of incorrect responses out of the total number of responses in each case.

Analysis of most frequently missed items.-- Table 5 shows the results on 11 items which were answered incorrectly by 25 per cent or more of those tested. The incorrect responses range from 26 per cent incorrect to 82 per cent incorrect out of the total group tested. The incorrect responses are further broken down in terms of the amount of formal education received. The table is described as follows: The item number in the questionnaire appears first. Next is shown the number and the per cent of incorrect responses of those patients having an elementary education or less than a high school education. The third column shows the number and per cent of incorrect responses of those patients having a high school education or one or more years of college. Next is shown the total number of incorrect responses. The last column shows the total percentage of incorrect responses. The last two columns are identical with columns 4 and 5 in Table 3.

Comparison of the two educational groups.-- The author of the questionnaire has stated that education plays a role,

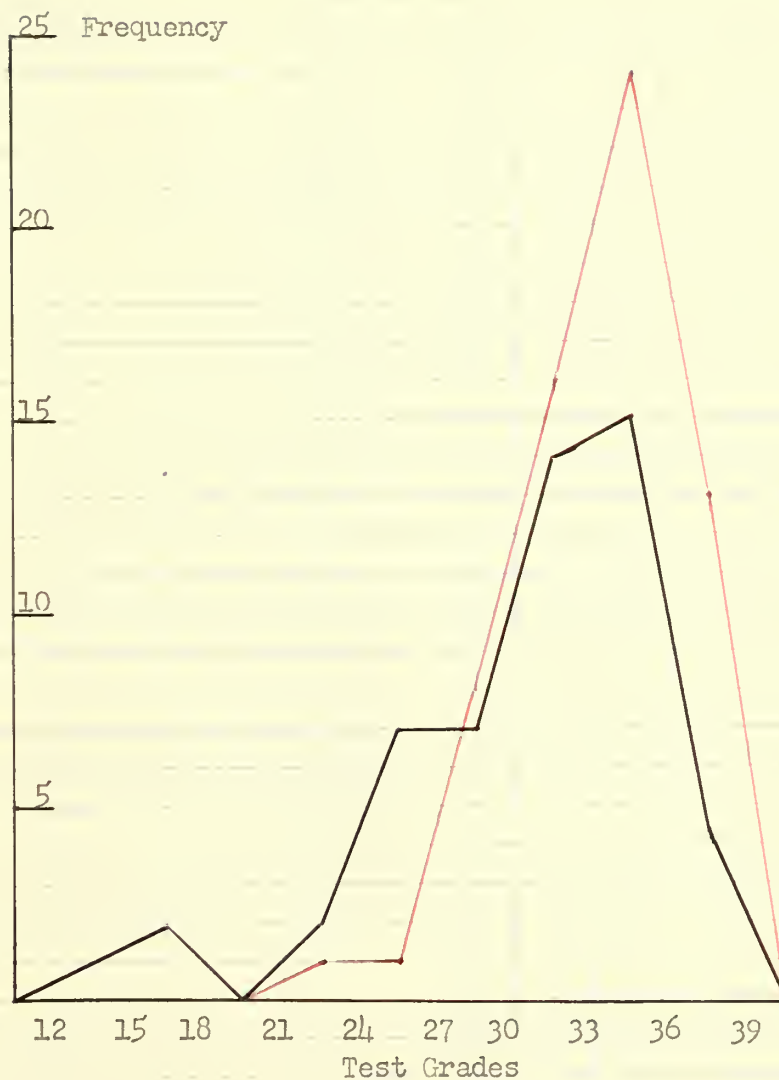
but not a conclusive role in answering the items on the test. Just how much of a factor, formal education was, can be noted from a comparison of mean and median scores for the group having an elementary but less than high school education, and the group having a high school or one or more years of college. The contrast is noted in Table 4. The highest possible score was 40. The scores for the elementary education group ranged from a low of 12 to a high of 38. For the high school group, the scores ranged from a low of 22 to a high of 38. The accompanying graph contrasts the scores of the two groups.

Table 4. Comparison of Mean and Median Scores for the Two Groups

	Mean Score	Median Score
Group having elementary or incomplete high school education.....	29.9	31
Group having high school or 1 yr. of college or more...	32.8	33

The ambiguous test items.-- The author has stated that there were 4 items (called X items because they could be interpreted either True or False) which were not used for scoring purposes but nevertheless they were considered of value in an item analysis. The value of the items lies in the fact that they exhibit certain attitudes which may or may not be correct. The four ambiguous items are as

Test scores shown graphically



Black line shows test scores for the group having an Elementary or less than a High School education.

Red line shows test scores for the group having a High School education or one or more years of college.

Table 5. Analysis of Items Answered Incorrectly by 25 Per Cent or More of Group

Item No.	Less than 12 Grades of Formal Education		12 Grades and Over		Total Answered Incorrectly	Per Cent of Those Tested
	No.	Per Cent	No.	Per Cent		
(1)	(2)		(3)		(4)	(5)
18	41	43.1	54	56.7	95	82.6
34	47	51.1	45	48.8	92	80.0
50	30	46.9	36	54.5	66	57.3
6	24	40.6	35	59.2	59	51.3
47	31	56.3	24	43.7	55	47.8
25	28	60.8	18	39.1	46	40.0
27	25	58.1	18	39.1	43	37.3
13	18	42.8	24	57.0	42	36.5
31	14	41.1	20	58.8	34	29.5
24	21	70.0	9	30.0	30	26.1
11	12	41.3	17	58.6	29	25.2

follows: ^{1/}

Item 21, "Once you have had tuberculosis you can't get it again."

Item 36, "Any job that makes you tired, no matter how little, is dangerous."

Item 39, "Once you have had tuberculosis you can't get married."

Item 45, "The best kind of job to get is an easy, sitting-down job."

^{1/}Items taken from Newman's test, op. cit.

Table 6 shows the various answers to the four items.

Table 6. Answers to the Four Ambiguous Items of the Questionnaire

Item No.	Number Answered True	Per Cent	Number Answered False	Per Cent	Unanswered	Per Cent
21	10	8.6	105	91.3		
36	89	77.3	21	18.2	5	4.3
39			113	98.2	2	1.7
45	73	63.4	33	28.6	9	7.8

Interpretation of test data.--- In trying to show a need for patient education concerning tuberculosis, an item analysis of the test results has been made. In trying to point out areas of misunderstanding concerning tuberculosis among patients, the eleven items most frequently answered incorrectly were selected. In other words, there were eleven items on the test which were missed by from 26 to 82 per cent of those tested. No direct conclusions can be drawn from this fact, however. One can only imply on the basis of such frequent incorrect responses, that there is at least some confusion in the mind of the patient concerning tuberculosis.

Implications of Test Data for Educational Planning

Test results show lack of proper information concerning tuberculosis.-- Certain implications might be drawn on the basis of frequent incorrect responses. For example:

Item No. 18, "Tuberculosis is more common among unskilled workers than among skilled." (Answer T)

Item 18 was incorrectly answered by 83 per cent of those tested.

Suggested emphasis for education: The value of a high standard of living, in order to combat disease, value of proper food, housing and sanitation.

Item No. 34, "The best time to plan for future work is"
 a. while you are in the sanatorium.
 b. after you are discharged.
 c. when the doctor tells you you are ready for full-time work.
 (Answer a) d. at no time since you really can't make plans.

Item 34 was incorrectly answered by 80 per cent of those tested.

Suggested emphasis for education: An explanation of rehabilitation as a form of treatment; a broader concept of treatment and aftercare.

Item No. 50, "The most dangerous period after discharge is"
 a. the next two to three years.
 b. the rest of your life.
 (Answer a) c. never dangerous once you are arrested.
 d. the next ten years.

Item 50 was incorrectly answered by 57 per cent of those tested.

Suggested emphasis for education: A thorough explanation of aftercare and the necessity for living a routine life; how to break away from hospital routine; the meaning of work tolerance.

Item No. 6, "Tuberculosis attacks everybody but is more common among the poor." (Answer T)

Item 6 was incorrectly answered by 51 per cent of those tested.

Suggested emphasis for education: Could be combined with Item 18 on standard of living.

Item No. 47, "Outdoor work is the best for the arrested."
(Answer F)

Item 47 was answered incorrectly by 48 per cent of those tested.

Suggested emphasis for education: Explanation of the changed viewpoint in regard to climate; the nature of the work performed as the determining factor. For example, pitching hay may be outdoor work but not desirable for the tuberculous person.

Item No. 25, "Treatment in tuberculosis is slow but it runs smoothly."
(Answer F)

Item 25 was answered incorrectly by 40 per cent of those tested.

Suggested emphasis for education: An explanation of the healing process and the necessity for complete bed rest when the disease is highly active.

Item No. 27, "It is best to have many and frequent visitors since they help to cheer you up." (Answer F)

Item 27 was incorrectly answered by 37 per cent of those tested.

Suggested emphasis for education: The importance of self-discipline in taking the cure.

Item No. 13, "It is of value to be overweight." (Answer F)

Item 13 was incorrectly answered by 37 per cent of those tested.

Suggested emphasis for education: The gaining of weight does not necessarily mean improvement, develops false sense of security.

Item No. 31, "It is possible for tuberculosis germs to remain alive outside the human body for weeks and still be able to cause tuberculosis." (Answer T)

Item 31 was incorrectly answered by 30 per cent of those tested.

Suggested emphasis for education: Characteristics of the tubercle bacillus, and how it is spread.

and the results of the investigation are as follows:

The first part of the investigation was devoted to the study of the general principles of the theory of the subject.

The second part of the investigation was devoted to the study of the special principles of the theory of the subject.

The third part of the investigation was devoted to the study of the application of the theory of the subject to the solution of the problems of the subject.

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The eleventh part of the investigation was devoted to the study of the application of the theory of the subject to the solution of the problems of the subject.

The twelfth part of the investigation was devoted to the study of the application of the theory of the subject to the solution of the problems of the subject.

The thirteenth part of the investigation was devoted to the study of the application of the theory of the subject to the solution of the problems of the subject.

The fourteenth part of the investigation was devoted to the study of the application of the theory of the subject to the solution of the problems of the subject.

The fifteenth part of the investigation was devoted to the study of the application of the theory of the subject to the solution of the problems of the subject.

Item No. 24, "The best way to fight worry is"

- a. to forget about it.
- b. to give it up since you will worry anyway.
- (Answer c) c. to face the problem squarely and try to get someone who can help discuss it with you.
- d. to fight it out yourself.

Item 24 was answered incorrectly by 26 per cent of those tested.

Suggested emphasis for education: The problem of worry can be lessened a great deal by the use of extra medical services such as library and social service.

Item No. 11, "It is easier to have peace of mind at home than in the sanatorium." (Answer F)

Item 11 was incorrectly answered by 25 per cent of those tested.

Suggested emphasis for education: A thorough explanation of the function of a sanatorium, so that the patient will get a clear picture of both his own problems and those of the medical and nursing staffs.

After considering Newman's test findings and the findings obtained in a local test situation, it would appear that there are areas of misunderstanding about tuberculosis in the mind of the patient, and hence a need for his education. If the need for the education of the patient is so great, what is being done about it? Has any organized effort been exerted toward the education of the patient? The following chapter describes what is being done to help solve the problem of patient education.

CHAPTER IV

DESCRIPTIONS OF CURRENT METHODS AND MATERIALS

Various Approaches to the Problem

Introductory statement.-- It is assumed that patients in general are educable and since tuberculosis is no respecter of persons we have every reason to assume that the general run of patients in sanatoria represent a cross-section of the general population. Evidence has been presented showing the need for patient education; therefore the problem is not, shall we teach, but rather, what to teach and how to teach. There have been some pioneering efforts which will serve to show that the problem of patient education is being recognized. Although much remains to be done, the efforts herein shown will serve as a guide for future planning in the development of educational programs for tuberculous patients.

Informal lecture and discussion method.-- In the municipal sanatorium at Otisville, New York, a series of illustrated lectures are given right after the patient is admitted. The lectures concern themselves with the important phases of tuberculosis including rehabilitation. Dr. Bobrowitz, ^{1/} the 1/I. D. Bobrowitz, M.D., The Problem of Tuberculous Patients Leaving against Advice, A Monograph, New York Tuberculosis and Health Association, 386 Fourth Ave., New York 16, N. Y., 1946. pp. 8-9.

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medical superintendent, has emphasized the need for an organized program of patient education and has suggested its scope in the following quotation:

There is a great need for intensive education of the patient. Definite plans should be made for this at the time of diagnosis and prior to admission to the institution, and while the patient is hospitalized. A proper approach to the patient at the time of diagnosis can build up his confidence, obtain his cooperation for treatment, and diminish the chance of a future discharge against advice. It should be emphasized that patients too often enter the sanatorium without a knowledge of tuberculosis and totally unprepared for treatment.

It will also be advantageous for the patient's family to have information about tuberculosis. The attitude of the family, and the relationships between the patient and family, frequently have a great bearing on the patient's acceptance of institutional care and his mental outlook to the cure.

An organized educational plan should exist in the institution. It will be much easier to convince patients to accept hospitalization until an arrest of the disease has occurred if they have been given information about tuberculosis. The instruction should enable them to understand their illness, know what the sanatorium does for them, appreciate their own responsibilities in getting well, learn how to prevent the spread of tuberculosis and to become acquainted with the methods of treatment. With this background they will understand the reasons given by the doctor for them not to leave against advice. This teaching should be arranged immediately after the patient's admission. Illustrated talks followed by periods for discussion and questions, I have found to be the most successful method. In addition, there are many valuable pamphlets, booklets, and motion pictures dealing with important topics in tuberculosis distributed by the National Tuberculosis Association. (Special illustrated material in their native tongue should be available for foreign language groups.) Patients should be encouraged to attend these lectures more than once.

The informal group discussion technique has also been highlighted in the program of education sponsored by the Bronx Tuberculosis and Health Committee for tuberculous patients. In a recent lecture, Miss Gladys Adams^{1/}, representing this Committee, stated that from her experience with patients, the technique of peaceful penetration was the best way to educate patients. She favors teaching with small groups of about twelve, rather than by means of the radio which she considers too impersonal. It is not a question of what you want to teach them but rather what the patient will accept. Informal lectures (twelve in all) are given every other week to small groups of ambulant patients. The lectures are given by a graduate nurse. The following is an outline of the lectures:

SYNOPSIS OF OUTLINE FOR
PATIENT EDUCATION
IN TUBERCULOSIS INSTITUTIONS

LECTURE I. COMPLETING YOUR CURE

Tuberculosis is curable
Famous men who had tuberculosis
Trudeau, Edward Livingston, M.D.
Laennec, Rene-Theophile, M.D.
Christy Mathewson--baseball star
Chopin, Frederic Francois--musician
Thoreau, Henry David--philosopher and writer

LECTURE II. TUBERCULOSIS--HOW IT IS SPREAD

What happens when germs enter the body

^{1/}Gladys A. Adams, R.N., Bronx Tuberculosis and Health Committee of the New York Tuberculosis and Health Association, "An Educational Program for Sanatorium Patients." Lecture given at a Health Education Institute sponsored by the Massachusetts Tuberculosis League and held at Simmons College, March 12, 1946.

Personal hygiene
Sputum, prevention of infection
How to deal with contaminated areas
Handwashing

LECTURE III. OLD VS. NEW BELIEFS

Climate
Diet
Open Air Treatment
Altitude
Heredity
Smoking and Drinking

LECTURE IV. CHEMOTHERAPY--DRUGS

Use of drugs--only when prescribed
Chemotherapy
Self-discipline--a necessity for the tuberculous
Mental attitudes of the patient

LECTURE V. DIAGNOSIS AND TREATMENTS

Tests and laboratory examinations
Mantoux
Sputum
Blood count
Blood tests
Gastric lavage
Gaffky count
Urine examination
Physical examination
X-ray
Rest
Pneumothorax

LECTURE VI. THE FAMILY OF THE TUBERCULOUS PATIENT

(Desirable to reach family before patient's discharge)
Need for their understanding and cooperation
Patient must continue under physician's supervision
Household routines must be adapted to his need
Education of family a necessity
Precautions essential if discharged patient has positive sputum
Examination of all family contacts
X-ray and tests: where patient is positive, all members of family should be under supervision

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LECTURE VII. THE DISCHARGED PATIENT

A.O.R.--Its implication regarding patient's recovery

Six classifications with explanation:

- a. Unimproved
- b. Improved
- c. Quiescent
- d. Apparently arrested
- e. Arrested
- f. Apparently cured

Prevention of relapse

Proof of teaching

Courage, discipline and intelligence

LECTURE VIII. RECREATION

Most suitable types

Avoidance of crowds, games of chance, late hours, strenuous exercise

Vacation period

Values of experience in use of libraries and occupational therapy for development of quiet hobbies

LECTURE IX. REHABILITATION

What does the physician advise on discharge?

Part-time work--how to use time

Full-time work

Suitability of old job

Need to learn new job techniques

What has been done in hospital in rehabilitation

Where patients may look for help

Local or State Tuberculosis Association

State Vocational Bureau

Fallacies of "out-door" types of work

Readjustment necessary for patients

LECTURE X. RESUME OF IMPORTANT POINTS

Approach to the problem of patient education through

radio.-- There is an increasing awareness of the need of utilizing various methods in the problem of patient education.

^{1/}Miss Fenton, writing in The Canadian Nurse, states some of

1/A. Edith Fenton, "Patient Education in Tuberculosis Hospitals," The Canadian Nurse, (May, 1946), 42: 401.

the possibilities in teaching methods:

Patient education, especially at the beginning, should be largely an individual matter, as there will be differences in intelligence, background, receptiveness, emotional stability, and sense of responsibility. We have heard of a sanatorium that uses a questionnaire at the beginning, as an appraisal of how much the individual already knows or does not know, and understands or misunderstands. The purpose of this is to give direction to educational efforts, to show where concentrated attention is needed, and to stimulate in patients a desire to acquire correct information.

As time goes by, other means of sharing information with the patient are useful. Opportunities in the daily contact of doctor, nurse, and patient are many and varied, and the value of incidental teaching should not be overlooked. Group teaching, through radio, lectures and movies, all have a place. In one Ontario sanatorium, during recent months, a medical question box has been conducted over the hospital radio. The patients send in questions, the interrogator is the public health nurse on the staff, and the answers are given by a member of the medical staff. The radio director reports that this program has an almost 100 per cent listening audience, according to survey. Lectures and movies can, of course, only be used for convalescent patients.

Middlesex County Sanatorium has also inaugurated a program of medical education for tuberculous patients by means of a central radio control system. The program consists of a series of eight lectures of from 20 to 30 minutes each, once per week for a period of eight weeks. The lectures are carried on by the medical staff and deal with the different phases of treatment. The eight lectures constitute the course and the course is offered every six months. The lectures reach all of the patients by means of individual ear-phones. The program has been in effect only for a very



short time, but it indicates an increasing awareness on the part of the doctors to the need for more patient education.

The value of the radio as a medium for patient education, lies in the fact that it is so universal in its effect. Every patient has an opportunity to profit from such instruction. The use of the radio, of course, has only been partially explored, and it will take a great deal of research in methods and materials to fully exploit such a valuable medium of expression.

Patient education through literature.-- The education of the patient by means of books and pamphlets has a definite value in any tuberculosis institution. Patients ask innumerable questions of doctors. If answers to their questions could be provided in printed form, it would save a great deal of the physician's time. Attempts have been made to gather some of the questions which seem most typical of all those asked by tuberculous patients, and to compile them in book form with their respective answers. Thus the book or pamphlet serves to supplement the advice of the physician. Long^{1/} has the following to say in regard to the power of education, in the treatment of the tuberculous patient:

In the often desperate struggle between man and tuberculosis Nature has selected for survival not only the patient with effective physiological and anatomical response to the inroads of the germ of the disease, but him also who has the will to

^{1/}Esmond R. Long, M.D., "Introduction" to Dr. Heise's book, op. cit., p. v.

battle and the good sense to profit by the many lessons offered in the course of this chronic illness.

The best educational method in tuberculosis, as in any other branch of knowledge, is that in which the initiative is taken by the student, and is expressed in the form of intelligent inquiry, not to be satisfied without well-founded knowledge based on wide experience.

In an effort to stimulate intelligent inquiry, on the part of the tuberculous patient, some books and pamphlets have been published in order to provide specific health education for the patient. The following represents some of the most effective literature at the present time:

1. 1000 Questions and Answers on Tuberculosis by Fred H. Heise, M.D., published by the National Tuberculosis Association, New York, 1941. The book contains approximately 1000 questions which represent the most frequent and important inquiries of tuberculous patients. The book is subdivided as follows together with some sample questions, answers to which are given in the book but are omitted here because of space limitations:

a. Heredity

Sample Question: Can one inherit a resistance or predisposition to tuberculosis?

b. Predisposition

Sample Question: What diseases may predispose one to tuberculosis?

c. Infection

Sample Question: How are tubercle bacilli taken into the system?

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- d. Immunity
Sample Question: Is there any such a thing as being immune to tuberculosis?
- e. Relapse
Sample Question: What usually causes a relapse of tuberculosis?
- f. Symptoms
Sample Question: Can one have bronchial trouble, cough and raise, and not have tuberculosis?
- g. Diagnosis
Sample Question: Are there any symptoms always indicative of tuberculosis?
- h. Terms and Definitions
Sample Question: Where is the apex?
- i. Classification
Sample Question: What is a minimal lesion?
- j. Cavity
Sample Question: What is the meaning of a cavity?
- k. Treatment
Sample Question: Please advise me what, besides going to bed, a tuberculous patient should do when he contracts a cold or sore throat.
- l. Surgical Treatment
Sample Question: What is meant by pneumothorax treatment?
- m. Laboratory Aids
Sample Question: What is the sedimentation rate and of what value is it in the diagnosis and treatment of pulmonary tuberculosis?
- n. Bronchoscopy
Sample Question: What is a bronchoscopy?
- o. Associated Diseases
Sample Question: What is tuberculous bronchitis?
- p. Extrapulmonary Tuberculosis
Sample Question: Can one have pleurisy and not have tuberculosis?

1. The first part of the report is devoted to a general survey of the situation in the country.

2. The second part of the report is devoted to a detailed analysis of the economic situation.

3. The third part of the report is devoted to a detailed analysis of the social situation.

4. The fourth part of the report is devoted to a detailed analysis of the political situation.

5. The fifth part of the report is devoted to a detailed analysis of the cultural situation.

6. The sixth part of the report is devoted to a detailed analysis of the scientific situation.

7. The seventh part of the report is devoted to a detailed analysis of the sports situation.

8. The eighth part of the report is devoted to a detailed analysis of the health situation.

9. The ninth part of the report is devoted to a detailed analysis of the environment.

10. The tenth part of the report is devoted to a detailed analysis of the future prospects.

11. The eleventh part of the report is devoted to a detailed analysis of the foreign relations.

12. The twelfth part of the report is devoted to a detailed analysis of the international situation.

13. The thirteenth part of the report is devoted to a detailed analysis of the world situation.

14. The fourteenth part of the report is devoted to a detailed analysis of the global situation.

2. Facts That Tuberculous Patients Should Know is a 19-page pamphlet prepared and edited by members of the Tuberculosis Committee of the Bronx Tuberculosis and Health Committee, of the New York Tuberculosis and Health Association, Inc. The committee was made up of three doctors and two nurses. An outline of the pamphlet with sample questions follows:

Infection

Sample Question: What is the cause of the disease tuberculosis?

Types of Disease

Sample Question: What does childhood tuberculosis mean when applied to an adult?

Symptoms

Sample Questions:

- (Cough) Do colds increase activity of the disease?
- (Sputum) Does negative sputum mean no activity?
- (Pain) What is the significance of pain in tuberculosis?
- (Temperature) What is the normal temperature?
- (Night Sweats) Why do some tuberculous patients have night sweats?
- (Hemorrhage) What would cause a patient to hemorrhage who has been curing for a year, and who has no sputum and no cough?
- (Pleural Effusion) What is a pleural effusion?
- (Shortness of Breath) In the fibroid type of tuberculosis is shortness of breath permanent?

Physical and X-ray Findings

Sample Question: Will an X-ray tell how long healing has been in progress?

1. General Information

The purpose of this report is to provide a comprehensive overview of the project's progress and to identify any potential risks or issues that may arise. The report is intended for the project manager and the steering committee. The information provided in this report will be used to make informed decisions about the project's future direction.

2. Project Objectives

The project objectives are to develop a new software application that will improve the efficiency of the company's operations. The objectives are to be achieved by the end of the project.

3. Project Scope

The project scope includes the development of the software application, the testing of the application, and the deployment of the application.

The project scope also includes the training of the users and the documentation of the application.

The project scope excludes the hardware and the network infrastructure.

The project scope also excludes the ongoing maintenance of the application.

The project scope includes the development of the software application, the testing of the application, and the deployment of the application.

The project scope also includes the training of the users and the documentation of the application.

The project scope excludes the hardware and the network infrastructure.

The project scope also excludes the ongoing maintenance of the application.

4. Project Schedule

The project schedule is as follows:

TreatmentSample Questions:

- (Diet) Is it possible to cure at home with a positive sputum?
- (Sunlight) Is exposure to the sun beneficial to a tuberculous patient?
- (Pneumothorax) What type of disease is most benefited by pneumothorax treatments?
- (Phrenicectomy) Please explain the phrenic nerve operation. Does the whole lung collapse? How long does the lung stay collapsed?
- (Thoracoplasty) What is thoracoplasty?

Results of Treatment

Sample Question: What findings are essential other than negative sputum tests for a period of six months to determine the arrest of tuberculosis?

Rehabilitation

Sample Question: When should work be considered for a patient whose tuberculosis has been arrested?

Marriage and Childbearing

Sample Question: Why is marriage harmful to tuberculous patients?

Prevention

Sample Question: What shall I do to protect my children? I expect to continue my cure at home in the near future.

Answers are provided for each question. The questions represent a cross-section of over 400 questions which were asked by tuberculous patients.

3. What YOU Should Know About Tuberculosis by Charles E. Lyght, M.D., published by the National Tuberculosis Association, New York, 1946. This publication, a 30-page pamphlet,

lists twenty-two questions which tuberculous patients in various localities frequently ask and provides rather comprehensive answers to each question. The questions considered are:

1. What is my outlook?
2. What caused my TB?
3. Did I get TB from a relative?
4. Where else might I have picked up TB?
5. Where do TB germs live?
6. How do TB germs behave inside my body?
7. Will TB attack anything besides the lungs?
8. Does TB give any early warning?
9. What does the tuberculin test tell us?
10. What do chest X-rays tell us?
11. Who gets TB?
12. Who recovers from TB?
13. What must I do to get back my health?
14. Why so much talk about rest?
15. Where is the freshest air in the U.S.A.?
16. How long will it take me to get well?
17. When may I begin to do things again?
18. What about care in my own home?
19. Is there a job I can fill?
20. What about homemakers?
21. Will my TB stay healed?
22. Where can I get further advice?

4. Huber the Tuber by Harry A. Wilmer, M.D., published by the National Tuberculosis Association, New York, 1942. Huber the Tuber tells the story of a tuberculous infection beginning with the actual inhalation of the bacilli, the natural defenses of the human body, the destructive power of tuberculosis, and the healing power of treatment. The complete story is told by means of cartoons, together with their interpretation. For example, in describing the inhalation of the germs into the body, the tubercle bacilli are described by means of cartoon characters such as the following, which

is an excerpt from the book:

HUBER THE TUBER, Nasty von Sputum, Rusty the Bloodyvitch, Huey the Long Tuber, and their friends left their old home. It was a hurried departure and quite involuntary. But they were carried away in the breath of a moment; during a cough they left on some droplets of moisture. (p. 2)

Wilmer describes the actual infection as follows,

Every new case of tuberculosis comes from an old case of tuberculosis. It is spread from one person to another by tubercle bacilli carried in droplets of moisture flying from the mouth and nose during coughing, sneezing, and talking. (p. 2)

The book is non-technical and can be understood by practically any tuberculous patient who is able to read.

Planning for effective use of available literature.--

The literature which has been described herein, is a definite attempt to educate the tuberculous patient in terms of his disease. The use of literature has not been widespread, however. Some medical directors feel that literature which is too technical may confuse the patient. Wilmer's book, Huber the Tuber, is probably the best attempt at the present time to eliminate any confusion in the mind of the patient. In order to determine what is best in health education literature, a coordinated effort must be exerted to make sure that patients within tuberculosis sanatoria receive the available literature provided it has been approved by the medical staff of the institution. It therefore devolves upon the medical director and staff to make an appraisal of existing literature to make sure that its value is exploited to the fullest

extent. The person in charge of the patient's library would be an ideal person to take charge of distributing health education to the patients.

Common Aspects of Current Programs

The need for flexibility in any program.-- Medical education programs for patients must be flexible enough to meet the varied backgrounds of tuberculous patients. Present programs and literature aim at improving the patient's present knowledge of tuberculosis, and stress the patient's responsibility to himself and to his family. Present education stresses the importance of taking treatment and continuing treatment until complete recovery. Facts such as the cause of tuberculosis, how it is contracted and how it is spread, are points which most physicians would agree as being essential and understandable to most tuberculous patients. However, it would appear that the more detailed the information concerning tuberculosis becomes, the more necessary it is to fit the instruction to the individual tuberculous patient. Each case of tuberculosis is as different as each individual personality. In this area of education then, as in all other areas, effective learning will take place as individual differences in need for education are recognized and as appropriate methods to meet individual and common needs are utilized.

Ultimate Aims of Educational Programs

Solving the problem of individual differences.-- How to give all patients the fundamental facts about tuberculosis and at the same time to provide a more enriched program of health education for the patient with a higher level of intelligence is the problem of health education for tuberculous patients. Let us assume that there are certain facts about tuberculosis which most doctors will agree upon, as being essential for all tuberculous patients. However, it would appear that, at some point there is a dividing line between what is necessary and understandable to all patients regardless of background and what is best for the patient with a more enriched background of education. The ultimate goal of patient education is to create a greater sense of responsibility on the part of the tuberculous patient, a responsibility to himself, to his family, and to society.

Group instruction and individual counseling.-- It would therefore appear that, in order to solve the problem of individual differences, two techniques for imparting instruction will be needed; namely, the group method and the individual counseling method. Both techniques will need to be utilized, depending upon the local needs, such as the size of the institution and the general level of education of the patients within the institution. For the tuberculous patient with an enriched educational background, and a thirst for

THE HISTORY OF THE UNITED STATES

of the American people, and the history of the United States, from the first settlement of the continent to the present time. The history of the United States is a story of the growth of a nation, from a small colony of English settlers to a great republic, which has become a world power. The story is one of the struggle for freedom, and the triumph of the principles of liberty and justice for all. The history of the United States is a story of the growth of a nation, from a small colony of English settlers to a great republic, which has become a world power. The story is one of the struggle for freedom, and the triumph of the principles of liberty and justice for all.

knowledge, the individual counseling method might be utilized. If the physician has enough time to spend with the individual, he might offer valuable advice and counsel for such a patient. It takes a great deal of adaptability to adjust to the routine of the sanatorium, particularly if a professionally trained person is placed in a room with a common laborer. The physician can do a great deal to stimulate intelligent inquiry on the part of the patient through individual counseling. The group method of instruction can be utilized with small groups, such as the type advocated by the Bronx Tuberculosis and Health Committee, or with large groups by means of the radio. In order to adequately solve the problem of patient education, both methods must be fully utilized.

CHAPTER V

SUMMARY, CONCLUSIONS, AND RECOMMENDATIONS

General Summary

Patient should understand the nature of his handicap.--

It has been pointed out that there is a need for the education of the tuberculous patient in terms of the limitations of his disease. The evidence that such a need exists has been based upon the following methods:

1. Facts pointing to the nature and magnitude of the problem of tuberculosis, which might suggest the need for more education.

2. Medical opinion which definitely suggests the need for the education of the tuberculous patient in terms of his handicap.

3. The results of a questionnaire administered to 115 tuberculous patients, and which shows the present status of information concerning tuberculosis, in the mind of the patient.

Attempts at the medical education of the tuberculous patient.-- It has been shown that there have been attempts toward the education of the patient. The attempts are by no means widespread. They vary with each individual institution.

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Probably the most universal attempt at the education of the tuberculous patient is through the medium of literature. The use of books and pamphlets designed for patient use is a method which is frequently employed.

Conclusions

Lack of any coordinated effort.-- It is apparent that doctors generally agree that the tuberculous patient should know something about his disease. There is, however, a lack of any definite method in approaching the problem of the education of the patient. Patients will trade off one doctor's opinion against another and as a result the patient becomes confused. When there is confusion and misinformation, there occasionally arises the patient who is known as a "sidewalk authority" who spreads misinformation. There is no place for the "sidewalk authority" in a well-organized patient education program. Patients who become tuberculosis authorities, tend to disrupt the morale of an institution. They tell the story of tuberculosis as it has affected them, and if by chance their progress has been slow, their viewpoint is colored by that fact. When new tuberculous patients come to an institution, they are quick to sense the morale of the place, if they are by chance placed in a large ward. Their first impressions have a great bearing on their future behavior in taking the cure. It is of utmost importance that the patient entering the sanatorium for the first time should get his

orientation from the doctor, firsthand.

Recommendations

The problem of tuberculosis has been shown to be fundamentally one of education. Health education for the prevention of tuberculosis, and more specifically, medical education of the tuberculous patient in order to control tuberculosis are both fundamental. Re-education and rehabilitation concern themselves with the problem of tuberculosis control. Since we are dealing with a chronic disease which may recur from time to time, the variable factor is the tuberculous patient and every effort must be expended to make sure that his medical care and hospitalization will not have been in vain. More and better treatment of the patient, as well as the disease, is necessary if tuberculosis control is to become more effective.

In establishing a basis for recommendations for developing programs of education in local organizations, there are certain underlying principles which must be accepted as axiomatic.

1. There is a need for the re-education of the tuberculous patient in terms of his disease and the limitations which it imposes upon him. The tuberculous patient must understand enough about tuberculosis to know why he must live within physical limitations, and such limitations must be taught to him while he is in the sanatorium.

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2. There is increasing agreement among medical authorities that this need should be met by an organized program of education in the sanatorium for all patients.

3. There is, however, no one best program for the medical education of tuberculous patients. There are various techniques and practices which might be effectively combined to make up a program.

4. In the development of an educational program, the basic consideration should be the needs of individual tuberculous patients. The differentiated needs of patients should be met by individual methods and the common needs of patients may best be met through group approaches.

5. The program should utilize local resources, both in terms of personnel and material. The most promising program is the one which is developed cooperatively by doctors and rehabilitation workers.

6. If local resources do not adequately meet existing needs, then additions should be provided both in terms of specialized professional service and in terms of needed equipment and supplies.

7. The program of education initiated in the sanatorium should not be considered completed when the individual is discharged. The rehabilitation program should serve to extend the educational program until the individual is satisfactorily adjusted.

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3. The total program of patient education should be evaluated from time to time to insure an effective and functional service.

Specific Suggestions for Initiating a Program for the Re-Education of the Tuberculous Individual

No attempt is being made here to set forth a comprehensive list of recommendations. However, certain suggestions can be mentioned to indicate how the principles can be implemented. The suggestions are offered under three headings, (A) Organization, (B) Content, and (C) Method.

A. Organization

1. A planning or advisory committee, made up of physicians with the medical director as chairman, could be organized to study the local situation. The committee could also include any lay people whom the medical director might consider helpful.
2. Specific responsibilities for the development of certain aspects of the program could be delegated to staff members qualified by training and personality to assume them.

B. Content

The content of any program could be determined by:

1. The use of Newman's questionnaire, "What Do You Know About Tuberculosis?" with the entire literate patient population of a tuberculosis institution.
2. Make a detailed item analysis of the test results in order to find out the areas of misunderstanding concerning tuberculosis among patients.
3. Call a meeting of the planning committee to discuss the test findings.

4. At a meeting of the planning committee, there could be a pooling of medical opinion concerning the various publications designed for patient use, and distributed by the National Tuberculosis Association.
5. Have the patients submit questions anonymously and discuss such questions at a committee meeting.

C. Method

The method to be employed will depend on the local situation. The following methods are offered as suggestive:

1. Each incoming patient should receive individual counseling at the hands of the physician most skilled in teaching. The counseling should concern itself with the nature of treatment, the demands it places upon the tuberculous individual, and particular emphasis upon the fact that the patient is an individual, and not just a pair of lungs.
2. Orientation lectures could be prepared for incoming patients by means of radio transcriptions to be played over the central radio system. Such a method would save the physician's time.
3. Questions could be asked by a lay person and answered by the doctor over the central radio system. Such questions and answers would be common to all patients in the institution.
4. A serial story could be developed depicting the life of a tuberculous patient after he leaves the sanatorium. The story could be dramatized at specific intervals on the central radio system.
5. Classes for ambulatory patients could be carried on with illustrated lectures by the physician.
6. The patients' library could be utilized with various readings prescribed for individual patients by the doctor.

First of all, I am very glad to hear from you. I hope you are well and happy. I have been thinking of you a lot lately. I am doing well, but I am a bit busy at the moment. I will write to you again soon.

I have been thinking of you a lot lately. I am doing well, but I am a bit busy at the moment. I will write to you again soon. I hope you are well and happy. I have been thinking of you a lot lately. I am doing well, but I am a bit busy at the moment. I will write to you again soon.

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Concluding statement.-- The recommendations offered herein are merely suggestive. Whether one or more are used or whether none are used is of no great concern provided something is done. It is of utmost importance that action be taken toward the education of tuberculous patients in terms of the limitations which the disease imposes upon them. If the basic principles are borne in mind, action must be taken toward the setting up of medical education programs in all tuberculosis hospitals.

Education of the patient is a tremendous gap which exists in tuberculosis control. The tuberculosis problem is partly medical, partly sociological, and partly economic; and education is a function of all three.

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January 1st, 1900. The first day of the new year.

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APPENDIX

There is available from several sources information concerning their health, training or employment status, history of progress both medically and vocationally since discharge. Assuming that a veteran may be considered to be making a satisfactory medical and vocational adjustment if he is well and progressing toward the vocational objective planned during treatment, statistics may show a significant difference between those who benefitted from counseling and those who did not.

Methods of Securing Data

1. Regional Offices: The cooperation of associates in various Regional Offices to which the cases were referred after discharge has been secured. Lists of names and questions can be forwarded to these men. This source should not be all inclusive but should supplement other sources.
2. Hospital Out Patient Service: Many former patients receive followup care at the hospital and are interviewed by a doctor who is interested in the study.
3. School Officials: The cooperation of school officials will lead to data needed for the study.
4. Correspondence with veterans: Direct questionnaire to veteran.
5. Social Service: The V.A. Social Service maintains a close supervision over former patients and will provide pertinent data which is not confidential.
6. Direct interview: Many former patients correspond and visit with the counselor and will be available for questioning.

Groups — Characteristics

With counseling:

Would they have made satisfactory adjustment anyway? These must have definite evidence of a contribution to adjustment

Without counseling:

The rehabilitation program provided patients receiving treatment for pulmonary tuberculosis at V.A. Hospital, Rutland Heights has been in operation for five years as of June 30, 1951. Vocational counseling is considered to be a vital part of this program. To accomplish the purposes of vocational advisement as required by the V.A. in conformance ^{with} ~~in~~ the provisions of P.L. #16 and P.L. #346 a full time counselor has been on duty since October 6, 1946. He is assisted by a full time stenographer and in addition has been assisted by a Psychometrist, the latter having been employed for approximately one half the life of the guidance unit.

It is felt that an evaluation of the effectiveness of this hospital counseling program is needed. A proposed outline ^{of} a problem in this area follows:

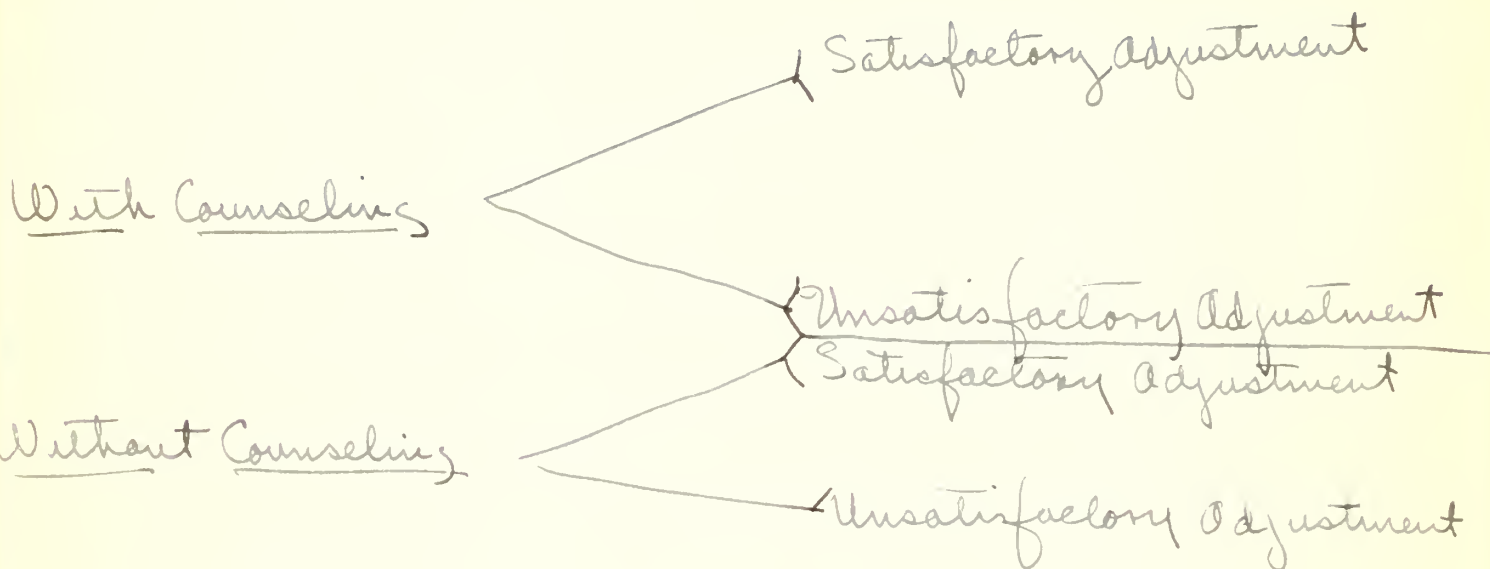
"What contribution does vocational counseling make to the physical, mental, social and vocational adjustments of patients discharged from the hospital?"

I. What objectives does hospital vocational counseling serve?

- A. Aids tuberculous patients remain well after discharge by assisting them select vocational objectives and training programs which will not aggravate their disease.
- B. Makes it possible to provide the advantages associated with "continuous rehabilitation".
- C. Enhances the benefits of hospitalization by reducing anxiety over future economic security and by assisting patients establish long-term vocational goals which motivate hospital educational therapy courses.
- D. Vocational success is more probable because of the opportunity to provide comprehensive vocational guidance techniques rather than shortened "appraisal" methods.
- E. Patients receive complete benefits derived from all services represented on the rehabilitation team, which relies heavily on the findings of the vocational counselor in meeting its responsibilities.

II. Rationale of the statistical study

During the period June 30, 1946 - June 30, 1947, 153 WWII veterans were discharged from VAH, Rutland Heights. Some of these men entered rehabilitation programs following vocational counseling--many did not, for a number of reasons. Since stability of health and ~~va~~ satisfactory vocational adjustment may be considered criteria of hospital counseling, a study of the characteristics of these 153 men may reveal facts pertinent to this evaluation.



With counseling
Those who

Without counseling
Those who

Satisfactory adjust : a) Progressed medically (remained ^{TB} inactive)
b) Progressed vocationally (training or work)

Unsatisfactory : a) Active TB remained active or inactive became ^{active}
b) No activity or vocational activity which is dangerous

	Satisfactory	Unsatisfactory	Total
	%	%	
With Counseling			
Without Counseling			

WHAT DO YOU KNOW ABOUT TUBERCULOSIS?

Name _____ Date of Admission _____

Date of Birth _____ Male or Female _____

Encircle the highest school grade completed: 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16

Chief occupation before illness _____ Today's Date _____

Part of the job in getting you well is to teach you all we can about tuberculosis so that you will understand the treatment, and what you can do to get well and stay well. But first we must find out how much you know about tuberculosis,

Inside this booklet you will find many statements. Some of them are true and some are false. Read each one carefully. Put a circle around T if you think the statement is true; if you think the statement is false, put a circle around F, as in the samples below:

Tuberculosis is an illness	(T)	F
Tuberculosis is incurable	T	(F)

The first statement is true and a circle is drawn around (T). The second statement is false and a circle is drawn around (F).

Some of the statements will have four answers to each. You are to decide which is the best answer and then put a circle around the letter for that answer, as in the sample below:

Tuberculosis is caused by	
(a) a germ	(a)
(b) an insect	b
(c) a dog bite	c
(d) bad air	d

Here (a) "a germ" is the best answer and a circle is drawn around (a) in the right hand margin.

All the statements refer to tuberculosis even though in the case of some of them the disease is not specifically mentioned. Please try to answer these statements as honestly and frankly as you can. It is only in this way that we can help you know all you should about tuberculosis.

WHAT DO YOU KNOW ABOUT TUBERCULOSIS?

- | | | |
|---|---|---|
| 1. It is possible to prevent the spread of tuberculosis. | T | F |
| 2. Early diagnosis generally means early recovery. | T | F |
| 3. Since many people recover from tuberculosis without ever knowing they had it, it is best to ignore early tuberculosis. | T | F |
| 4. Early tuberculosis may have no symptoms. | T | F |
| 5. You get tuberculosis | | |
| a. by being born with it. | a | |
| b. from someone who has it. | b | |
| c. by having weak lungs. | c | |
| d. because you can't prevent it. | d | |
| 6. Tuberculosis attacks everybody but is more common among the poor. | T | F |
| 7. Tuberculosis may strike | | |
| a. mainly children. | a | |
| b. mainly young adults. | b | |
| c. mainly older people. | c | |
| d. at any age. | d | |
| 8. Successful athletes have been found to have tuberculosis. | T | F |
| 9. In tuberculosis, the less you know about the disease, the better off you are. | T | F |
| 10. The closer the contact you've had with a tuberculous patient the greater the chance to get tuberculosis. | T | F |
| 11. It is easier to have peace of mind at home than in the sanatorium. | T | F |
| 12. Since treatment in tuberculosis takes so long, delay in treatment makes little difference. | T | F |
| 13. It is of value to be overweight. | T | F |
| 14. Each case of tuberculosis is different. | T | F |
| 15. Tuberculosis that affects other parts of the body than the lungs is not serious. | T | F |
| 16. The best way to get inside information about tuberculosis is to ask the patients who have been sick a long time. | T | F |
| 17. Symptoms appear more often with advanced tuberculosis. | T | F |
| 18. Tuberculosis is more common among unskilled workers than among skilled. | T | F |
| 19. Climate is the most important part of treatment. | T | F |
| 20. Treatment at home is | | |
| a. better than in a sanatorium. | a | |
| b. all right for housewives. | b | |
| c. advisable only when a sanatorium is not available. | c | |
| d. all right if you're not positive. | d | |
| 21. Once you have had tuberculosis you can't get it again. | T | F |
| 22. You should stay out in the sun as much as possible. | T | F |
| 23. Tuberculosis only attacks the lungs. | T | F |
| 24. The best way to fight worry is | | |
| a. to forget about it. | a | |
| b. to give it up since you will worry anyway. | b | |
| c. to face the problem squarely and try to get someone who can help discuss it with you. | c | |
| d. to fight it out yourself. | d | |
| 25. Treatment in tuberculosis is slow but it runs smoothly. | T | F |
| 26. Negative sputum means no tuberculosis activity. | T | F |
| 27. It is best to have many and frequent visitors since they help to cheer you up. | T | F |
| 28. In discussing your illness and symptoms, | | |
| a. discuss them with the older patients. | a | |
| b. only discuss them with the doctor. | b | |
| c. discuss them with the nurse. | c | |
| d. do not discuss them with anyone. | d | |

WHAT DO YOU KNOW ABOUT TUBERCULOSIS?

- | | | |
|--|---|---|
| 29. You should try to set a time limit on how long you will stay in the sanatorium. | T | F |
| 30. The best way to judge how you are getting along is how you feel. | T | F |
| 31. It is possible for tuberculosis germs to remain alive outside the human body for weeks and still be able to cause tuberculosis. | T | F |
| 32. Having peace of mind is important in the cure. | T | F |
| 33. Anyone who has had tuberculosis can recognize it in others. | T | F |
| 34. The best time to plan for future work is | | |
| a. while you are in the sanatorium. | a | |
| b. after you are discharged. | b | |
| c. when the doctor tells you you are ready for full-time work. | c | |
| d. at no time since you really can't make plans. | d | |
| 35. You should try to increase your activity as quickly as you can once you are ambulatory. | T | F |
| 36. Any job that makes you tired, no matter how little, is dangerous. | T | F |
| 37. An arrested case of tuberculosis may be a safer companion than a person who has never been examined for tuberculosis. | T | F |
| 38. The most important treatment in tuberculosis is | | |
| a. food | a | |
| b. medicine | b | |
| c. fresh air | c | |
| d. rest | d | |
| 39. Once you have had tuberculosis you can't get married. | T | F |
| 40. If you feel all right, you are all right. | T | F |
| 41. The best ways to kill possible tuberculosis germs are by boiling and burning. | T | F |
| 42. Once you become ambulatory and the illness inactive, it is all right to go home without a discharge. | T | F |
| 43. When you are at home, the only necessary precaution is that you have your own room. | T | F |
| 44. A patient who leaves against advice has just as good a chance to get well and keep well as the patient who stays until discharged. | T | F |
| 45. The best kind of job to get is an easy, sitting-down job. | T | F |
| 46. After you are discharged, | | |
| a. routine and regular check-up is necessary. | a | |
| b. medical check-up is necessary only when you don't feel well. | b | |
| c. medical check-up is not necessary if you take care of yourself. | c | |
| d. medical check-up is not necessary if you are discharged as arrested. | d | |
| 47. Outdoor work is the best for the arrested case. | T | F |
| 48. People who have tuberculosis | | |
| a. cannot ever lead a normal life. | a | |
| b. can get back to a pretty normal life. | b | |
| c. can have a normal life only with other tuberculous patients. | c | |
| d. should stay in a special settlement only for tuberculous patients. | d | |
| 49. In spite of good intentions to help the discharged patient, nothing can really be done. | T | F |
| 50. The most dangerous period after discharge is | | |
| a. the next 2 to 3 years. | a | |
| b. the rest of your life. | b | |
| c. never dangerous once you are arrested. | c | |
| d. the next 10 years. | d | |

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